Chronic Kidney Disease

Summary Overview: ‘Increasing the Uptake of Home Therapies’

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This report presents a summary overview of the Chronic Kidney Disease (CKD) work stream within the West Midlands Central Health Innovation Education Cluster (WMC-HIEC). It summarises and synthesises the findings from three separate reports conducted by members of the CKD team. The report proposes a tentative model of
the factors implicated in increasing the uptake of home therapies. This is a speculative model and would require further testing and integration with reports from other WMC-HIEC work streams.

This summary supplements the three separate CKD team project reports but also needs to be considered alongside all other work streams that linked to CKD activity within the WMC-HIEC project:

- Demonstrator site projects
- Simulation theme
- Service evaluation/service improvement theme

These three work streams are reported separately and their findings or recommendations are not integrated within this summary.

Nevertheless, this summary contextualises the separate but overlapping Simulation and Service Improvement work streams and the Demonstrator site projects managed by the Service Improvement Lead. Renal Centres were the participant sites for all the demonstrator site projects and for the Service evaluation work; CKD was also the focus for some of the simulation theme work.

All the WMC-HIEC work stream reports stand alone but each also explored or investigated different aspects of the overall technical, clinical, cultural and behavioural aspects of the Renal Services system which may influence the take up of Home Therapies. As such, their outcomes overlap or are interlinked and should be considered in conjunction with each other when considering options to achieve systemic change in the future. Further work would be needed to integrate and synthesise all the outputs from the WMC-HIEC project. Some of the identified suggestions and recommendations are being taken forward by the University of Birmingham CLARHC team, while other identified opportunities that do not align with the CLARHC are being taken forward by partners emerging during the course of the WMC-HIEC project. Selected examples of these continuing activities are described in this summary to illustrate the legacy created by the WMC-HIEC.
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Section 1: Introduction

The West Midlands Central Health Innovation Education Cluster (WMC-HIEC) was one of nineteen collaborative projects funded by the Department of Health in 2010. Three awards went to the West Midlands and these projects reported to the West Midlands Strategic Health Authority (now Midlands and East). The WMC-HIEC project was focused towards quality enhancement, aiming to explore innovative partnerships between education, NHS organisations and industry to catalyse innovation in safety, effectiveness and patient experience. The WMC-HIEC project was grounded in the notion that health care is a socio-technical system whose outcomes depend on the interactions between the attributes of staff and the system in which they operate. Two cross cutting topics (one technological and one clinical) were identified as vehicles for exploration of these quality and innovation challenges. These were Chronic Kidney Disease and Simulation technologies.

During the contract negotiation the SHA decided that the WMC-HIEC CKD topic should be aligned with complementary work being planned by the Specialist Commissioners together with the West Midlands Renal Network and this was agreed after a series of alignment meetings. This collaboration continued until the end of the WMC-HIEC project.

Historically, home dialysis was the norm, but over the last two decades, Haemodialysis (HD) has become increasingly centralised, being delivered either in NHS units within acute hospitals or in satellite units, some privately owned or franchised to the main industry providers.

Policy drivers, including commitments to patient choice, better understanding of quality of life factors plus clinical and technological advances have brought the focus back towards home delivery of RRT. Peritoneal dialysis (PD) and nocturnal home haemodialysis (HHD) have helped generate clinician and patient experience of managing a full life alongside ESRD. The Department of Health (2009) now recommends that HHD should routinely be offered as part of a full menu of renal replacement therapy options, including transplantation, peritoneal dialysis and conservative management but the take up has not been as rapid as anticipated. A number of clinical, risk, social, economic and psychological factors appear to be
implicated and the WMC-HIEC intended to explore some of these factors in order to evolve and catalyse solutions.

There is evidence to suggest that home haemodialysis is clinically effective, results in higher quality of life and longer survival time than Centre-based haemodialysis (Mowatt et al, 2003; Ageborg, Allenius and Cederfjäll, 2005; Saner et al, 2005; Kjellstrant et al, 2008). Home delivery of dialysis, through home haemodialysis or peritoneal dialysis, has been shown to be cheaper and more cost-effective than either hospital-based haemodialysis or satellite-unit based haemodialysis (Baboolal et al, 2008; NICE, 2002; Winkelmayer, 2002; Mowatt et al, 2003; McFarlane et al, 2006; Agar et al, 2005a,b; Ananthapavan et al 2010). The NICE guidance (2002) stated that HHD was cheaper than hospital HD and should be offered to all suitable patients.

NHS Kidney Care (2010a) suggests that home haemodialysis, particularly nocturnal HHD, offer improved quality of life and better physiological status, through the opportunity to undertake more frequent or longer dialysis sessions, associated with improved survival, reduced blood pressure, medication, symptom burden, hospitalisations plus freedom from dietary and fluid restrictions. Despite these benefits, only 2% of the prevalent dialysis population undertook HHD in 2000/2001 (NICE 2002).

The ability to dialyse nocturnally and for longer hours enabled by home delivery of dialysis may be key to improvements in patient wellbeing, and allows greater freedom for patients to maintain employment and a better lifestyle (Agar et al 2005b, Bolgg and Hyde, 2006; Mowatt et al, 2003; Kutner et al, 2005, Mitra 2011). Patients value greatly the ability to maintain a sense of control over their health and treatment (Polaschek, 2007; Giles, 2005). However, spouses and relatives, acting as carers, may experience additional stress as a result of the increased demands on them to assist in dialysis at home (Polaschek, 2007; NICE 2002).

However, there are criticisms of the existing evidence and reliable current data is lacking in the UK, not least because a critical mass of patients undertaking HHD is lacking. These factors may partially explain why, despite the acknowledged advantages of home delivery of dialysis, wide variations persist in the availability of home haemodialysis internationally. Identified barriers to home dialysis include;

The literature suggests that patients may not be presented with home dialysis options or do not receive sufficient patient education about different treatment modalities (Mehrotra et al, 2005, Mitra 2011). It has been shown that increased numbers of patients choose home dialysis following patient-centred educational interventions (Manns et al, 2005; McLaughlin et al, 2008; Agraharkar et al, 2003). NHS Kidney Care produced a toolkit for establishing a successful home haemodialysis programme (NHS Kidney Care, 2010a). This toolkit stresses the importance of training and support for patients and carers, and also of patient choice. The importance of improved education for healthcare professionals has also been recognised (Piccoli et al 2003, Blagg 2005). However, there remain a number of groups who tend not to be considered suitable for home therapy, including individuals with complex or unstable co-morbidities, people who live alone and older people.

In the western world, diabetes is one of the highest single causes of kidney disease (US Department of Health and Human Services 2011, UK Renal Registry 2005). Hypertension, diabetes, obesity, smoking and socio-economic status are all risk factors for kidney disease. Risk factors and disease progression are compounded by all the factors implicated in social deprivation. (NHS Kidney Care 2010b). Furthermore, in the UK, an older client group with co-morbidity is increasingly the norm. In 2004, 10% of service users were managing four or more long term conditions (DoH 2004). This suggests a group of patients with complex clinical presentation and increasing risk of frailty. Increasing the uptake of HHD may necessitate reviewing these traditional exclusions as well as reaching a better understanding of the smaller take up of HHD options by black and ethnic minority groups.

There is no doubt that that patient attributes influence therapy options and outcomes. CKD has a negative impact on overall quality of life. Though many patients adjust successfully, CKD is associated with poorer psychosocial functioning, higher anxiety, higher distress, decreased sense of well-being, higher depression rates and negative health perception. An economic evaluation that estimated quality of life scores for
people on dialysis found that quality of life scores were consistently lower than age-related population norm. The study also found that dialysis places a major limitation on a patient's social life. About 80% of the sample on dialysis felt that their life was affected, with 60% reporting a burden on their carers (Roderick 2005, NHS Kidney Care 2010a).

CKD also increases the risk of hospitalisation, morbidity and mortality. In England the mortality rate where the underlying cause of death is chronic renal failure has remained relatively static at about 1.3 to 1.8 per 100,000 people. In England this equated to 10,030 years of life lost prematurely in under 75 year olds in the combined years 2006/08. (NHS Kidney Care 2010b).

In summary, diagnosis with CKD initiates a journey of progressive physical and psychological change that could potentially expose the individual to the impact of any fragmentation of care and services or changes in their health and social, economic or psychological wellbeing. Transfer into RRT is a further disruptive and stressful transition even if preparation is excellent (Corben & Rosen 2005). The WMC-HIEC CKD work stream proposed to explore some of the factors implicated in that journey.
Section 2: Project Aims and Objectives

The overall aim of the WMC-HIEC CKD topic was to work in partnership with academia, industry and NHS staff in the West Midlands Renal Centres for adult patients to explore ways of increasing the uptake of home dialysis. We were particularly keen to enable participation and involvement by service users and carers and although renal services for children were excluded from the brief, transferable learning from children’s renal services was utilised to inform ideas about involvement.

Chronic Kidney Disease (CKD) is usually a long term condition which can have an acute or a more gradual onset:

\[ \text{a condition that cannot be cured but can be managed through medication and/or therapy} \quad (\text{DOH 2011}) \]

The WMC-HIEC team were oriented towards exploration of gradual onset which more frequently allows advance planning and preparation for RRT. We did not specifically explore the clinical care needs arising from the types of Acute Kidney Injury (AKI) which may lead to unplanned entry to a CKD pathway or dialysis and result in short, medium or long term kidney failure. However, particularly towards the end of our project worked more collaboratively with the East Midlands HIEC who were exploring AKI. This collaboration is described later in this summary.

Our agreed focus was towards patients using or preparing to enter RRT. These patients would be experiencing End Stage Renal Disease (ESRD) at Stage 5 of the CKD pathway as described in the NICE guidelines (2008):
Table 1. Stages of chronic kidney disease

<table>
<thead>
<tr>
<th>Stage</th>
<th>Glomerular filtration rate: GFR (ml/min/1.73 m²)</th>
<th>Description</th>
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<tr>
<td>1</td>
<td>&gt; 90</td>
<td>Normal or increased GFR, with other evidence of kidney damage</td>
</tr>
<tr>
<td>2</td>
<td>60–89</td>
<td>Slight decrease in GFR, with other evidence of kidney damage</td>
</tr>
<tr>
<td>3A</td>
<td>45–59</td>
<td>Moderate decrease in GFR, with or without other evidence of kidney damage</td>
</tr>
<tr>
<td>3B</td>
<td>30–44</td>
<td>Moderate decrease in GFR, with or without other evidence of kidney damage</td>
</tr>
<tr>
<td>4</td>
<td>15–29</td>
<td>Severe decrease in GFR, with or without other evidence of kidney damage</td>
</tr>
<tr>
<td>5</td>
<td>&lt; 15</td>
<td>Established renal failure</td>
</tr>
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(Taken from NICE 2008)

However as this is only one stage of a whole patient journey, it was also imperative to consider how experiences and decisions made earlier in the pathway may influence Stage 5.

Similarly, although our project was aligned with the SHA’s primary interest in increasing the uptake of Home Haemodialysis (HHD), this modality could not be examined in isolation. Renal Replacement Therapy options (RRT) include Haemo and Peritoneal Dialysis and it was clear from clinical experts and patients alike that at different points in the patient journey, both methods are options for home management and could be offered with different degrees of assistance or independence from the Renal Centre.
Section 3: Project Structure

In the original project proposal document, the WMC-HIEC development team identified that collaboration and efficiency require three types of process: data collection, data analysis and knowledge dissemination and brokerage. These principles informed each stage of the CKD work stream.

3.1 Communication and involvement strategy

The CKD work stream was conducted in two successive Phases; the design of the second phase was informed by the findings from Phase 1. Every phase and subsection of the work was designed through collaboration and discussion with stakeholders.

The main aim of our communication and involvement strategy was to facilitate debate between groups who had not traditionally met together. A stakeholder group was convened, with open invitations being extended to the SHA; the WMC-HIEC Advisory Board and, Project team; Regional and national HIEC network; WM Renal Network: WM Specialist Commissioners; renal centre staff from each Centre in the West Midlands; service users and carers; Kidney Patients Association; Kidney Care UK; researchers; educators; industry partners and the two main commercial providers.

This group did not achieve a membership which was as wide ranging as initially hoped, but it did broker connections between stakeholder groups who were not already meeting together. However, it was also important not to duplicate the functions of existing groups and networks and after the third monthly meeting, it was decided to review the terms of reference. The group became an open network which continued to bring together academics and researchers, renal centre staff and service users and carers by meeting at four monthly intervals to promote evidence based debate and to share and disseminate good practice. Three successful, well evaluated shared learning events were organised between September 2011 and September 2012. Each event looked at a different aspect of the home therapies challenge. One event focused on staff and commissioner perspectives; the second was focused around service user and carer perceptions, needs and experiences and the final event service as the dissemination event to consult on the findings of the CKD topic Phase 1 and 2 work. This event culminated in a closed meeting where
service user and carer members generated a set of recommendations for further work which are presented in Section 4.

3.2 Phase 1

Following alignment discussions with the Specialised Commissioning Team, the WMC-HIEC team consulted Renal Centre staff about the uptake of home therapies. We emphasised our independent researcher status as it was felt important to reassure staff that we were not undertaking a scrutiny exercise on behalf of the Commissioners. Ethical approval was awarded by the University of Birmingham Ethics Committee. Although the Phase 1 work was a consultation rather than formal research nevertheless research principles were followed to ensure consistency and rigour. All projects adopted a qualitative approach; data was gathered via semi structured interviews, member checks were conducted for accuracy and data were subjected to thematic analysis using an appropriate methodology. Trustworthiness was enhanced by sharing the findings with participants before confirming the emergent themes.

The Phase 1 consultation was in two phases:

i) A series of initial visits to establish access and collaboration took place between April and June 2011. Together with a review of the research evidence, these were used to inform

ii) follow up telephone interviews with lead nurses and physicians responsible for increasing the uptake of home haemodialysis, staff with responsibility for patient flow data and renal technicians. These interviews took place in August and September 2011.

i) The aims of the initial visits were:

- To establish contact and identify the most relevant personnel for further follow up enquiry, in order to minimise intrusion by the WMC-HIEC team
- To define the scope of the consultation
- To explore the overall capacity of the unit by type of therapy and caseload;
- To explore staff perceptions of the unit strengths and weaknesses
• To identify aspirations in terms of improving the uptake of home therapies by enquiring ‘If you could do one thing to improve the uptake of home therapies, what would it be?  
• To understand the flow of patients through the clinical pathway  
• To gain permission for further follow up contact to enable more detailed consultation  
• To begin to identify primary research questions which would comprise a second phase of the work stream  
• To begin to identify possible areas for small collaborative project/pilot work for the WMC-HIEC Service Improvement and Simulation work streams subsequently to facilitate with the Renal Centres. These small projects were intended to test out some of the local ideas for increasing the uptake of home dialysis, to provide vehicles for continuing partnership working between industry, academia, renal services and service users and carers.

ii) Each follow up interview aimed:  
• To explore individual staff views about the uptake of home dialysis services by patients with CKD in that Renal Centre  
• To explore progress towards the CQUIN target to increase the uptake of home dialysis and identify how the Renal Centre was working towards this goal  
• To investigate the haemodialysis equipment, explore the technical capacity and limitations of each Renal Centre and any technology impact in terms of increasing the uptake of home dialysis  
• To understand the flow of CKD patients taking up dialysis at that Renal Centre  
• To understand the provision of education and support to staff, patients and carers  
• To enquire about the numbers of CKD patients and the proportion taking up home dialysis at the Renal Centre.

iii) Concurrently, members of the CKD team conducted a mapping exercise to establish the extent and timing of education about CKD in undergraduate and postgraduate medical and nursing programmes among universities across the West Midlands region.

iv) Strenuous attempts were also made to establish a collaborative relationship with the two main commercial providers of HHD equipment, in order to understand liaison
between the industry leads and NHS organisations in new product design and patient education.

Existing research literature was reviewed to give a baseline for comparison and to help shape the focus of the consultation. Knowledge from other WMC-HIEC work streams also contributed. Findings and information were analysed and synthesised into a report submitted to the Specialist Commissioning Team in September 2011. The outcomes were also used to devise proposals for further work in Phase 2. These proposals were discussed and reviewed with Renal Centres and a number of projects were agreed with negotiated aims.

3.3 Phase 2

For pragmatic and administrative reasons, the Phase 2 work was divided into two linked strands, each strand comprising several projects. One strand was co-ordinated by the Service Improvement Theme Lead, the other by the CKD topic lead. All projects were approved by UoB ethics Committee and also, where deemed appropriate, via the Integrated Research Approval System (IRAS). Local Research Governance procedures were followed and approvals gained in each participating NHS Trust.

3.3.1 Phase 2 Strand One:

This comprised two formal research projects: one exploring the educational role of nurses in to facilitate the transition towards home therapies, the second exploring service user and carer needs and expectations from peer support. The peer support project explicitly explored some aspects of service user needs to help inform a parallel but separate project being undertaken by the WM Renal Network to pilot a model of peer support.

a) Educational role of Nurses

The Phase 1 CKD report 'Increasing the Uptake of Home Therapies (Beavan et al 2011) identified that the challenge for renal centres is to move the culture to a position where home therapies are the default modality of choice with alternatives considered only where there are compelling clinical, social or psychological factors, or when an individual patient exercises informed choice.
Nurses play a pivotal role in enabling patients to move from recipients of haemodialysis care to self-managed service users, we were curious about how nurses could achieve this whilst delivering safe, effective and patient centred clinical care. Similarly, it was important also to understanding how patients perceive this transition towards independence.

Renal Centre colleagues agreed this was a worthwhile inquiry. It was agreed to undertake an evaluation of the ways nurses promote the uptake of home haemodialysis during dialysis sessions.

The research questions were identified:

- How do haemodialysis nurses view their roles in caring for, educating and training patients?
- How do haemodialysis nurses encourage patients towards self-management?
- What formal and informal education and training of patients is undertaken during dialysis sessions?

b) Facilitating the participation of renal patients and carers in peer support

The second project in Strand one of the second phase evolved from one of the findings from the Phase 1 report (2011), which suggested there may be real benefits in developing the role of peer supporters. The aim of this research was to explore from a patient and carer perspective their needs, wants and expectations of peer support. It also examined how barriers to take-up of peer support may be overcome and recommended service improvements.

Identified research questions:

- How do patients and carers view peer support?
- What would patients and carers ideally want to gain from peer support?
- How can any perceived problems and barriers in taking up peer support be overcome?
- How would patients and carers prefer peer support to be made available?

3.3.2 Phase 2, Strand 2: Demonstrator Site Projects

The Phase 1 consultation had elicited ideas from renal centre staff for small projects which they felt had potential to stimulate an increase in the uptake of home therapies, but which they were unable to undertake because of resource limitations (usually
staff capacity). A menu of ideas was generated which renal staff and WMC-HIEC team felt would be feasible within a short time scale but which had potential to make a measurable difference. The menu of options was used to inform a series of negotiations with renal centres to identify host sites and to broker agreement between centres who wished to work in partnership on specific project. To catalyse these projects The WMC-HIEC team offered to contribute both capacity in terms of time and HIEC resources, and capability in the form of research expertise. In return, the host sites were asked to participate in the audit and evaluation work to be undertaken within the WMC-HOEIC Service Improvement Theme. Three demonstrator site projects were identified and were managed by the Service Improvement Theme lead.

i) Focus groups and interviews with patients to explore factors influencing their decisions about therapy

ii) Observations to investigate how staff-patient communication might influence choice of therapy options

iii) Development of a simulated fistula and how the design might be optimised for use in patient education and staff training

These Demonstrator site projects proceeded in parallel with the Service Improvement evaluations and with the two Strand 1 research projects so the various WMC-HIEC team members were very mindful of the need for clear boundaries and communication with the renal centres to ensure, firstly that our presence was as minimally intrusive as possible, and secondly, that renal centre staff knew who was the key contact for their particular project.

During the WMC-HIEC CKD project, a number of opportunities also arose to contribute to the work of others, or to take forward work that was not directly related to the WMC-HIEC work streams but was nevertheless of relevance to the overarching aim to improve quality in terms of safety, effectiveness and patient experience. Three examples are described in Section 4 to illustrate this type of wider partnership working.

These, together with the outcomes of the Phase 1 and Phase 2: Strand 1 projects are discussed in the next section. The demonstrator site and simulation project outcomes are reported separately by the respective leads.
Section 4: Project Outcomes; Key themes from project outputs and findings

This section summaries key points from the projects undertaken during the CKD work stream Phases 1 and 2.

It is important to emphasise that this summary does not represent a detailed report of every project undertaken in the CKD work stream. As previously mentioned, it does not incorporate findings from the Demonstrator site projects, nor integrate findings from either Simulation or Service Improvement themes. Instead, this summary contextualises those separate reports and discusses aspects of the CKD work stream not reported or discussed elsewhere.

All the WMC-HIEC projects, including the CKD Phase 1 and 2 projects and the other CKD oriented projects undertaken by the Service Improvement and Simulation Theme leads, plus the demonstrator site projects have resulted in a comprehensive project report, including a literature review and detailed sections covering methodology, findings and discussion. Each concludes with recommendations for future work. This summary supplements but does not replace those more detailed reports. Such synthesis and integration would require a longer timescale and an approach that was not achievable within the constraints of the WMC-HIEC remit. For this reason, this report should be read in conjunction with, not instead of other WMC-HIEC CKD reports. For ease of access each of the reports underpinning this summary is prefaced by an Executive Summary.

Identified aspects of the CKD outcomes (e.g. around service improvement, home therapies and the management of long term conditions) are being taken forward by the University of Birmingham CLARHC team

4.1 Phase 1

Initial visits to six of the Renal Centres highlighted that each had a distinctive culture and mix of caseload. All Centres were seeking ways to achieve the CQUIN target and to expand their Home Therapies services; some Centres had established new posts specifically for this purpose.
The range of perceived barriers to the uptake of home therapies were closely aligned to those identified in the literature. The main findings from the follow-up interviews with doctors, nurses and technicians were distilled into five main themes:

1. High commitment from renal staff  
2. A focus on achieving the CQUIN target  
3. The limitations imposed by facilities and resources, chiefly dedicated space and staff time  
4. The need for better data to assist benchmarking, quality monitoring and patient tracking  
5. The role of technology, which was seen to be a catalyser of progress when cultural barriers such as education and beliefs were addressed.

From these themes, the key barriers to stimulating the uptake of home therapies were identified as organisational, human behaviour and resource issues. Education, training, availability of support and a sound therapeutic alliance were all identified as important factors in effective clinical care. Patient confidence in every aspect of the delivery system may be the most important single factor. A macro-level perspective of the dynamic inter-relationships of factors influencing the uptake of home therapies was presented using an adapted version of Porter’s Five Forces Model (1980), to serve as a vehicle for continuing debate.

Renal Centre staff interviewed during Phase 1 advocated the advantages of home therapies but reported this was not necessarily replicated across the whole team. The availability of resources to develop home therapies which are personalised, sustainable and highly reliable is a substantial concern to Renal Centre staff. There was confidence about reaching the CQUIN target, but some staff expressed concern about resource constraints, the importance of timely and tailored patient education, and retaining patient choice. Analysis of Renal Centres’ workforce skills mix could explore processes to optimise patient care.

Centres were already implementing a range of quality enhancement initiatives, including better patient tracking, more timely patient education, greater use of patient champions, and assisted and minimal care programmes.
Technology and home environment were not perceived as major barriers. However, gaining permission for necessary adaptations in the home appears to present an obstacle for patients living in rented accommodation or communal settings.

Opportunities for greater patient and carer involvement were identified, together with a need to consider different approaches to patient and carer involvement. A need for further work was identified around: the psychological impact of shifting care into patient homes; education for staff, patients and carers; the health, social and economic aspects of investing in home therapies; and, optimal ways to embed best practice. There were also some indications that underlying culture may be an issue amenable to change. We understood ‘culture’ to be a composite of systemic factors, attitudes and human behaviour.

Our desire to explore and more fully understand these factors informed the evolution of the Demonstrator site projects and the design of the Phase 2 research projects.

4.2 Phase 2: Strand 1

As indicated above, Phase 2 comprised two separate strands of work. Strand 1 only is summarised in this report. This strand comprised two qualitative research projects, one with a focus on staff education and training needs, the other sought to understand patient and carer needs for peer support.

a) The staff focused project explored the educational role of nurses in facilitating the transition to Home Therapies.

This research explored the following questions:

- How do haemodialysis nurses view their roles in caring for, educating and training patients?
- How do haemodialysis nurses encourage patients towards self-management?
- What formal and informal education and training of patients is undertaken during dialysis sessions?

Interviews were conducted with nurses involved in delivering in-centre dialysis to explore the ways that nurses promote the uptake of home haemodialysis during the treatment session. Findings highlighted the complexity of effectively delivering patient centred care. It is a very challenging enterprise for nurses to appraise patient needs from moment to moment and adjust their communication accordingly (Coget 2010).
Nurses must constantly balance and prioritise clinical or instrumental care needs with socio-emotional needs and integrate this appraisal with their knowledge of the individual social and cultural context to judge the optimum moment to fulfil their educational role (Edelmann 2000). Patient wellbeing and needs vary from session to session and at different points within each session so receptivity to education and discussion about home therapies varies from moment to moment. Each individual nurse also brings their own social and cultural beliefs and experience to inform their approach. Power and authority, empathy, reciprocity and skills available all interact in a dynamic interchange which cannot be pre-determined by a protocol. Nevertheless, the findings indicate possible opportunities to make more consistent or effective use of dialysis sessions to encourage the beliefs, attitudes and behaviour change necessary to move along the transition to either self-care or home dialysis. For example, although nurses are very busy at the beginning and end of dialysis sessions, there may be opportunities to make more use of time when dialysis is under way.

The research findings considered how decisions are made about treatment modalities and day to day variables and how the underpinning therapeutic alliance supported or hindered these decisions. These factors are discussed in relation to managing the difficult balance between patient choice and skilful, non-coercive direction. Other systemic and cultural factors are also considered. For example, how decisions are made about patients who may be considered clinically unsuitable, unwilling or unable to dialyse at home. Opportunities to make greater use of self-care as an enabling method of increasing patient skills and confidence are also discussed in the research report.

Caring is integral to the role of a nurse. Recent reports highlight the outcomes when care and compassion are not invested. However, the research undertaken suggests the possibility that where nurses are perceived (or perceive themselves) primarily or solely as carers, this can limit the potential for patient self-efficacy and empowerment. Underlying beliefs about the nurse role in managing the balance between caring and enabling may be influential in determining the degree of facilitation offered to move a patient towards self-care. Inarguably this is a difficult balance to achieve and the suggestion is likely to elicit robust discussion as there is no automatically ‘right or wrong’ balance. However, achieving these challenging adjustments is part of the continuing challenge that nurses manage when working
with patients living with a long term fluctuating condition. Further work would be needed to understand more fully how underlying and fundamental beliefs influence professional behaviour.

This research study also identified the importance and value of patient to patient education and how this informal education is given considerable credibility by patients and carers. This aspect of facilitating the transition was investigated in more depth in the second Phase 2; Strand 1 study, summarised below.

b) The patient and carer oriented project explored barriers and enablers to facilitating the participation of renal patients and carers in peer support

The research questions explored:
- How do patients and carers view peer support?
- What would patients and carers ideally want to gain from peer support?
- How can any perceived problems and barriers in taking up peer support be overcome?
- How would patients and carers prefer peer support to be made available?

Peer support may be delivered in a range of different ways in terms of mode, format, duration, personnel and intended outcomes. Discussions with staff at Renal Units in early 2012 indicated that a variety of informal and formal approaches to peer support were being used with variable levels of take-up.

Existing research suggests that peer support is popular amongst patients who are users. Nonetheless fewer patients take-up peer support than express an interest in such support. Yet accessing peer support can be beneficial in helping patients with chronic kidney disease (CKD) adjust to their illness, make choices and alleviate fears about possible therapies (Perry, 2005; Hughes et al, 2009; Greenhalgh et al, 2006).

The study has achieved a better understanding of what patients and carers need, want and expect from peer support and identifies how actual or perceived barriers to the take-up of peer support by patients and carers may be resolved.
The term ‘peer support’ was not universally well understood, so there may be a need for clearer definitions and information. Nevertheless, peer support is perceived by both patients and carers to be distinct from and supplementary to the care offered by clinical staff and friends or family. The study identified a substantial overlap between patients and carers regarding the perceived benefits and attributes of peer support. Carers identified a need for peer support as much as did patients. The carers of HHD patients appear to have particularly pressing needs to help them to adjust to their new role and responsibilities; they reported side-lining their own worries and concerns during the treatment decision making process.

A number of practical, emotional and psychological barriers to accessing peer support were identified which affirm and extend existing literature. The study identified that receptivity and needs for peer support may vary over time, so flexibility of provision is needed. Most of all, a majority of respondents were very wary of appearing ‘needy’ or to be labelled as ‘not coping’ so it appears to be important that peer support is a constituent of the ‘normal’ menu of options routinely offered by staff as part of a clinical care plan and promoted positively by clinical staff. An appealing peer support relationship was described as a reciprocal sharing, rather than a one way gift of help. Establishing rapport was also considered important if the peer support encounter is to be successful. To better establish rapport, patients and carers wanted to be involved in choosing their own peer supporter. This was particularly important for patients (and their carers) choosing HHD as their modality and may perhaps indicate a desire for a sense of greater control over their illness and treatment.

This project took place in parallel with a West Midlands Renal Network pilot to roll out a telephone model of peer support across the West Midlands. The two projects were independent but aligned and some of the recommendations made in the WMC-HIEC peer support study have been incorporated into the WM Renal Network pilot, most notably, the offer of face to face meetings between peer supporter and recipient in advance of continuing telephone contact.

This project and the Phase 1 project also identified some of the advantages of a wider network of information, support and knowledge exchange. The next section describes some selected examples to illustrate how the CKD work stream enabled
networking and collaboration across the wider health economy. This brokering function is one of the legacies created by the WMC-HIEC

4.3 Links to the wider health economy

As identified in Section 3, opportunities arose to contribute to the work of others, or to take forward work of relevance to the overarching WMC HIEC aim to improve quality. Three selected examples are used to illustrate this type of wider partnership working:

4.3.1 Simulation team: Collaboration with East Midlands HIEC

Contact was made with East Midlands HIEC who were exploring Acute Kidney Injury (AKI). Their team had developed a cost effective tool for early identification of AKI and piloted this in an acute hospital setting with good results. The screening could easily be incorporated into normal screening tests for patient groups known to be at risk of kidney failure (e.g. patients attending or admitted with conditions linked to diabetes or hypertension). East Midlands HIEC team had also developed a training tool to raise awareness among junior doctors and clinical staff; this had been well evaluated and yielded evidence of effective learning. The East Midlands team now wanted to test out both the screening and the education tool in other locations including Primary Care. The Simulation theme lead for the WMC- HIEC is a practising GP as well as a Research Professor and agreed to take this project forward in the University of Birmingham and the Birmingham health economy.

During these discussions, the East Midlands team developed an interest in the WMC-HIEC Simulation work, exploring the potential of haptics\(^1\) to increase clinical safety by contributing to medical education. Jointly it was agreed to develop a haptics model to train medical staff in renal biopsy and evaluate the effectiveness in terms of safety and cost effectiveness

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**1 Haptic technology** uses tactile feedback to control virtual objects, and to enhance the remote control of machines and devices. Haptic approaches have been used in a variety of ways in medicine, for example to train surgeons in new techniques such as keyhole surgery, thus achieving a level of competence and expertise in a virtual environment before working with patients.
4.3.2 Service User and Carer perspectives

A key intention of the CKD work stream was to stimulate participation, collaboration and explore ways to improve involvement service users and carers in service evaluation and improvement. Substantial efforts were made to ensure service user and carer involvement in the stakeholder group and to create opportunities for service user and carer views and needs to be shared and debated with renal centre staff and researchers. Links were established with the Chairs and Secretaries of the Kidney Patients Association in each renal centre and each centre was also asked to put us in touch with both patient activists and those with experience of home dialysis, particularly those who had experience of HHD. Service users were invited both as delegates and keynote speakers at a regional HIEC event to all the CKD stakeholder meetings. One of the CKD shared learning events was focused entirely around service user experiences, including both keynote speakers and pre-filmed presentations so that service users and carers unable to attend in person could be represented. Renal centre staff reported that it was a powerful learning experience to discuss their clinical and organisational aspirations and challenges together while service users reported how useful it was to gain a better understanding of the political and organisational drivers and constraints. The CKD dissemination event concluded with a closed meeting for service users and carers. This meeting was chaired by a service user and their recommendations for further work were presented to the CKD team. Service users and carers acknowledge that some of these recommendations may be unfeasible or unrealistic, but were nevertheless a reasonable wish list. These recommendations were:

To increase the uptake of HHD, the CKD Service user and care forum recommended:

- There is a need for patient oriented minimum standards of care/provision for home therapies
- Best practice is not universal; variations across the country by Trust, SHA and nationally in provision, choice and service quality are unacceptable.
- NICE guidelines appear to be interpreted very differently and not universally adhered to
- Communication needs to be improved: both skills in communication for individual staff, and communication between Renal teams and other professional staff (e.g. GP’s)
• GP’s, Counsellors, Psychologists, Dieticians all need to be core members of the renal team. These staff need to be available routinely at clinics
• Service Users and Carers representation is insufficient; there is a need to review the engagement and involvement strategy and to resource this activity realistically
• More joined up integrated working is needed with Local Authorities (housing, waste disposal services, social services)
• Choice of machines dictates degree of continuity between Centre and home treatment; preparation for home therapies should include a more personalised choice of machine and training needs to be specific to the machine that will be installed at home
• It is helpful to create opportunities for patients to get together at an event, shared experiences convey practical tips and useful insights
• Technology (www, Skype, social media) can facilitate linking up and should be exploited
• Patients need education too: a patient who is not taking an interest in their treatment may have a lesser quality of life and increased morbidity/mortality
• Renal Centre staff jobs should not be put at risk by a move to home therapies: their skills and experience needs developing to make their redeployment into the community more cost effective
• Even though not all the original aims have fully been achieved, WMC-HIEC CKD project work was not a waste of time: gathering and sharing information has an impact; raises awareness and encourages reflection and critical review. Knowledge exchange is vital to stimulate service improvement

4.3.3 Sexuality and long term conditions
Service users identified a need for information, advice, support and the possibility of referral to specialist services to address concerns and difficulties managing their intimate and sexual relationships alongside the many challenges and transitions of living with CKD. Physical, medical, emotional, psychological and iatrogenic factors exert and influence on self-esteem, sexuality and sexual function as well as the energy and wellbeing resources to invest in relationship building and maintenance. Outline research proposals were submitted to several possible sources of funding to enable further exploration of sexual, intimacy and relationship support needs but none were successful. However, the CKD topic lead has linked with researchers within the UoB CLARHC who are interested in exploring sexuality and sexual needs
among patients managing long term conditions and a bid to a suitable NIHR call is currently being developed. It is hoped this may enable both a systematic review and a collaborative action research project to improve patient information, clinical care and staff education. Without the WMC-HIEC, it is unlikely these links between researchers would have been made.

4.3.4 Local Research Governance processes
During the development of the CKD projects, the team became familiar with internal and external ethical scrutiny processes and also the local Research Governance process within NHS Trusts. The Integrated Research Ethics System (IRAS) has speeded up and, to a degree, simplified applications for approval to undertake research in NHS organisations, but local Research Governance systems do not appear to have kept pace. Despite approachable and courteous local staff, considerable inconsistencies, and delays were experienced, together with wide variations in the requirements within individual Trusts which necessitated considerable duplication. NHS staff also reported frustrations with the local systems which felt cumbersome, inefficient and time consuming, particularly as NHS staff were frequently managing research governance roles alongside other substantial responsibilities.

Because of the number of researchers from a range of organisations who contributed to the WMC-HIEC project it was evident these difficulties were not isolated instances. There was no scope to investigate this issue within WMC- HIEC time but two partner universities (University of Wolverhampton and Birmingham City University) contributed staff time to enable a small working group to be convened. This was convened and co-ordinated by the CKD topic lead, so ensuring outcomes were fed back to the WMC-HIEC. This working group compiled and submitted an evidence based paper to the Health Research Authority (HRA). We subsequently met with the CEO and Director of Innovation and Collaboration at the HRA and are actively contributing to the HRA plans to review and redesign local research Governance processes and systems.

This is a further example of the legacy created by the WM-HIEC and the continuing networking and collaboration will ensure West Midlands NHS Organisations and universities help inform and shape HRA policy and practice.

4.3.5 Education Mapping
A fourth exercise was undertaken, to identify and map across all universities in the West Midlands region where CKD related topics are taught in the undergraduate and postgraduate curricula. A comprehensive mapping was completed but yielded such a diverse and incomplete picture that it was decided not to proceed with further explorations. Most education providers considered renal disease a postgraduate specialism. In some universities, CKD and renal therapies are included in undergraduate learning about long term conditions or in relation to specific age groups; for instance in children’s nursing programmes. In others, CKD is not covered at all, though there is inevitably transferable learning, for instance in behavioural and communication sciences curricula.

Gaining a more coherent picture and achieving a critical analysis of provision mapped against future workforce needs or in relation to mandatory and essential skills would require a whole system approach and resources beyond the scope of the WMC-HIEC project. However, the current re-organisation of commissioning structures and development of Local Education and Training Committees and Boards may enable this type of investigation to be revisited.

In the next section, these outcomes are considered in relation to the original overarching aims of the WMC-HIEC project.
Section 5: Discussion

This section incorporates the findings of the three Phase 1 and Phase 2 CKD projects into a tentative model to explain factors implicated in increasing the uptake of home therapies. The WMC-HIEC project was focused towards innovation and change to improve quality (of life and of services) for patients managing ESRD who are either in receipt of renal replacement therapies, or likely to require RRT in the future. The model helps contextualize the outcomes from CKD focused work from other WMC-HIEC work streams (which are reported separately by their theme leads and considers how these have contributed to achieving the original aims of the WMC-HIEC project.

This section also incorporates a short reflective commentary on learning derived from the experience of working in a new and innovative type of partnership. The experience of partnership is not explicitly discussed within other reports but is worthy of reflection. Collaboration, partnership and the need to devise different ways of working are all frequently discussed within current health and social care policy (e.g. DoH 2009b, 2010) and effective partnerships are crucial to the success of the new NHS Commissioning structures enacted by the Health and Social Care Act (2012) and the forthcoming health, social care and welfare reforms. There is potential to derive valuable learning from the lived experience of bringing together, from a range of cultures, a group of competent, dedicated and motivated individuals, each with their own area of expertise to work collaboratively towards a collective aim while continuing with their separate priorities.

The overarching aim of the WMC-HIEC was to work in partnership with education, research, industry and practice to develop a culture that promotes innovation and investigate factors that promote or inhibit innovation. For a number of political, pragmatic and partnership reasons, CKD and Renal Services became a primary vehicle for the investigation and exploration which contributed to achieving the overarching aim. In the process, the entire WMC-HIEC team developed a genuine and lively interest in CKD, together with a sincere respect for the challenges encountered by patients, carers and staff. Some of these challenges are specific to the experience of living with CKD; others are common to other long term conditions so some of the findings and suggestions for further work may be transferable to other long term conditions.
The Phase 1 report identified a range of cultural, behavioral, psychological, organizational and systemic factors which were implicated in the rate and pace of innovation and change. Findings from Phase 1 also identified that technology has potential to catalyse rather than restrict service innovation and that specific housing policy factors were barriers for patients living in rented accommodation. These factors were further explored during the CKD Phase 2 work and during the Demonstrator Site, Service Improvement and Simulation themes.

### 5.1 The challenge for Renal Services

By the end of the Phase 1 consultation and development work, the WMC-HIEC researchers were able to identify many of the dynamic inter-relationships of factors influencing the uptake of home therapies. These factors were presented using an adapted version of Porter’s Five Forces Model (1980) and used to articulate the key challenge faced by renal services.

The inter-related factors identified from CKD Phase 1 are listed in Figure 5.1.

**Figure 5.1: Interdependent factors implicated in the uptake of home therapies**

<table>
<thead>
<tr>
<th>Organisational factors</th>
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<tbody>
<tr>
<td>Availability of training resources</td>
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<tr>
<td>Patient involvement in training and education</td>
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<tr>
<td>Patient flow as a process</td>
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<tr>
<td>Flexible delivery models of RRT</td>
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<tr>
<td>Collaboration, competition and commissioning</td>
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<td>Working effectively with commissioners</td>
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<td>The impact of the CQUIN</td>
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<table>
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<tr>
<th>Factors related to Human Behaviour</th>
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<tr>
<td>Psychological impact of moving dialysis closer to home</td>
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<tr>
<td>Culture, including staff commitment</td>
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<tr>
<td>Staff and patient education and training</td>
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<tr>
<td>Role of simulation in cost effective education and training</td>
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<td>Sharing and dissemination of best practice</td>
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<table>
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<tr>
<th>The Potential of Technology to support and catalyse uptake</th>
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The key challenge is to enable the whole system, including commissioners, policy makers, educators, workforce planners, researchers and providers to work in partnership to enable a shift to a position where home therapies are the default choice unless there are compelling reasons (e.g. clinical or social risk, economic factors and patient choice). A whole system cultural shift is needed, which is beyond
the capacity and capability of any one organisation to achieve alone. In particular, it is crucial to ensure sufficient resources are made available to support clinically led change, since staff are frequently fully absorbed in managing the moment by moment decisions involved in meeting the clinical emotional, psychological, and social needs of patients and carers (Coget 2010)

Inarguably, this shift, or process of transformational change is already well under way but may not yet be as coherent and collaborative as it needs to be in order to achieve optimal outcomes. There are real opportunities in the current embryonic health and social care system to build a critical mass of ‘push towards’ knowledge, experience and confidence which will eventually have sufficient momentum to overcome the factors which currently limit the uptake of home therapies as a therapy of choice for ESRD. Renal services already have experience of achieving mass culture shift: the reverse transformation towards centre-based services occurred some decades ago. Clinicians who remember or experienced the previous home based culture may have an important role in encouraging and supporting colleagues who have no mental image to guide their thinking about the necessary service redesign and workforce development.

The collective aim of the WMC-HIEC CKD topic was to explore the forces needing to be managed in order to catalyse the pace of change already in progress. The outcomes of the CKD Phase 2 projects are summarised in Figure 5.2 below. This uses an adapted Lewin’s force field model (1951) to consider the factors driving and opposing the development of a culture oriented towards home therapies. Figure 5.2 is a tentative model derived from the CKD work stream. It does not integrate the outcomes of demonstrator site projects, or the Simulation and Service Improvement work streams but from informal discussion among the WMC-HIEC team, it appears highly likely these work streams have identified complementary and overlapping factors affecting the necessary whole system cultural shift.

Lewin (1951) suggested that, within any system in a process of transformation, change is both stimulated and restrained by a range of ‘push’ and ‘pull’ factors creating an equilibrium which needs to be addressed in order for change to proceed. The collective aim of the CKD topic was to explore the forces needing to be managed in order to catalyse the pace of change already in progress to generate a culture oriented towards home therapies
It is important to acknowledge that restraining forces may or may not be intentionally subversive. Lewin (1951) argued that the driving forces are (usually) positive, reasonable, logical, conscious and economic, while the restraining forces are (usually) negative, emotional, illogical, unconscious and social or psychological. When managing or reacting to change, it is crucial to accept both sets of forces as real and needing attention rather than making judgements or debating the right and wrong of diverse perspectives.

Building a critical balance sufficient to overcome the state of equilibrium is not achieved by an exercise of power but by skilfully working to resolve resistance while facilitating the promoting factors. Increasing the driving forces is not enough for change, because the restraining forces remain and may also increase their resistance exponentially. As long as they remain in place it becomes harder to use the driving forces. Therefore unless both the driving and restraining forces are balanced a reversion will occur after every forward movement, so even if change is achieved it is fundamentally unsustainable. Lewin (1951) suggested that change would be easier and longer lasting if the forces against change were reduced, rather than the forces for change being increased.
Lewin’s (1951) model proposes three steps in order to achieve sustainable change:

1. **Unfreezing** – this step reduces the strength of forces which maintain current equilibrium. Awareness raising, team discussion and reviewing the evidence are possible strategies.

2. **Moving** – this is a stage of scoping, which responds particularly to collaboration and consultation to develop new organisational values, attitudes and behaviours to help move the system onwards.

3. **Refreezing** – this is a period of stabilisation (which may be very short) so that changes can be consolidated and a new equilibrium achieved before continuing to review and develop.

Appraising some of the drivers and limitations to change may be helpful to incorporate into planning for the continuing development of a home therapies service. The final section of this discussion highlights some of the learning about working in partnership, derived during the process of the WMC-HIEC CKD work stream.

**5.2 Reflective commentary: The experience of partnership working:**

The investment of time and planning necessary to create successful partnerships for innovation should not be underestimated. Working in collaboration or partnership necessitates attention to underlying beliefs and cultural differences which inform behaviour. High level communication, listening and negotiation skills are needed to manage tacit and overt conflict. Tensions are normal and inevitable, to some extent essential as the group itself forms a micro-social system which may accurately reflect diversity within the wider academic and practice health community. Edelmann (2000) suggests it is more constructive to acknowledge tensions transparently and openly otherwise these can continue to exert a destructive impact, even if unconscious.

Partnership is a challenging enterprise requiring sustained and continued dialogue which values all involved as equal contributors of expertise, together with flexibility and creativity. Popay and Williams (1998), Finch (2000), Macpherson et al (2001) and Gutteridge and Dobbins (2010) found that effective partnerships in health and social care require ownership and commitment by staff and strategic leadership to
support the process and to enable the resources. Gutteridge and Dobbins (2010) argue that achieving meaningful involvement is not cost neutral but it can provide a value for money strategy, especially by catalysing knowledge transfer for innovation and integration of best practice.

We learned that in order to generate good quality and relevant outputs, it is important to take time to plan, to be flexible and to remain task and outcome focused while ensuring developmental discussion; this can be a new experience for cultures which have become increasingly target driven.

Although feedback from our service user and carer colleagues made it clear the CKD team had not fully resolved all the barriers to full partnership, we received encouraging feedback and the substantial efforts made were acknowledged. For the future, there is substantial transferable learning from initiatives to involve service users and carers (e.g. Tew et al 2004). There has been a greater and longer focus on partnerships with and for service users than between organisations and expert groups and the structural, organisational and cultural challenges may be similar. For example, working to involve mental health service users, Tew et al (2004) identified five levels of involvement and argued that for clarity of expectations and communication, it is vital to determine which level is appropriate for the project in hand.

It was clear that renal centre teams were managing very significant workloads. The WMC-HIEC project took place during a time of systemic re-organisation in preparation for the Health and Social Care Bill (2012) and in a climate of increasing cost improvement pressures. It is easy for research and innovation to become subsumed under the everyday workload so it is crucial that adequate resources, infrastructures and support are set aside to facilitate clinically led, patient centred service change.

It must be acknowledged that some participants both inside and external to the WMC-HIEC were ambivalent about the value of exploring the mechanics and process of partnership. There were also indications that although clinicians welcomed research a greater privilege was awarded to clinically focused research rather than research focused towards organisational or systems development. Finally, there is a tension to be managed between robust research design and methods and achieving speedy and tangible deliverables. Further work would be
required to clarify these perceptions, which do not reflect either the NHS Research and Development Strategy (DoH 2006) or the Health and Social Care Act (2012). Both place considerable emphasis on the role of research in high quality services. A local initiative by Wolverhampton PCT was reported as a case study on the Social Partnership Forum and identified a number of ‘top tips’ for successful partnership working. Top of the list was the need for a genuine desire and commitment, initially from the top of both management and staff side. Continuing positive leadership throughout is needed to identify the change agents and develop a set of shared or joint aims, values and principles. Wide ranging consultation is identified as important, together with tenacity and a determination to resolve conflict.

For the future, the following suggestions may help develop effective partnerships with the least possible delay:

**Project Organisation**

- Build-in to the design a timescale that offers maximum opportunity for good quality outputs and/or build in a flexible planning period post finding award to allow for delays e.g. in ethical approvals
- Plan a detailed dissemination strategy at the earliest point and conserve budget to enable this
- Continue dialogue to reduce and eliminate institutional and administrative barriers
- Ensure sufficient project management capacity to ensure support and facilitation, speedy and effective infrastructures and efficient, timely process

**Partnership development**

- Seek out and make use of every opportunity to network and consult widely
- Continue partnership initiatives and use these as opportunities for reflexive learning.

- To facilitate effective partnership working:

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2 from the Social Partnership Forum website, an alliance between DoH, employers and Unions to promote effective partnership working: http://www.socialpartnershipforum.org/casestudies/Priority2/Pages/PartnershipworkingatWolverhamptonCityPrimaryCareTrust.aspx. accessed 08.04.12)
- Take time to establish shared and common goals
- Clarify the contract and expectations at the start to minimise the opportunities for later confusion about decision making authority, responsibility, channels of reporting, budgets and accountability

It can be very helpful to consider the desired level of partnership and explicitly negotiate this at different points in the project. The balance need not be a once and for all fixed entity. Pratt et al (1999) explain that partnership requirements change during the life of a project and that partnership behaviours also need to be flexible and adaptable. They proposed a typology of partnership behaviour intended to help Primary Care project groups and organisations appraise the type of collaboration and involvement desired and purposefully to facilitate the behaviours most likely to meet the needs of the partnership at different stages of evolution. This is shown in Figure 5.3.

**Figure 5.3. A typology of partnership behaviours**

[Diagram showing a typology of partnership behaviours]

The model is not intended as a hierarchy, but illustrates a range of options for partnership behaviours. The horizontal axis represents the continuum of goals sought; from individual to collective. The vertical axis represents the predictability of solutions and objectives, and the extent to which the behaviours needed to achieve these are known in advance. In the upper quadrants, only broad aims can be recognised and achieving these is dependent on working with and facilitating change.
in the behaviour of partners. Resilient, effective partnerships contain elements of all four quadrants and are likely to move between them over time.

The final section of this summary draws the discussion together and makes some suggestions for continuing work.
Section 6: Conclusion

The original WMC-HIEC project proposal suggested that building capacity for innovation has many components, requiring supportive leaders, an imaginative, motivated and energetic workforce, sound infrastructures and a dynamic environment that is prepared to improve quality and/or efficiency. The CKD work stream has investigated a number of factors that have potential to inform leadership decisions, increase effectiveness, safety, efficiency and improve patient and carer experience. These are all important components of quality enhancement. However, substantial time is needed to establish robust and sustainable partnerships and short funding timescales are insufficient to establish full impact and demonstrate sustainable long-term outcomes. Nevertheless, the type of networking and dissemination achieved by the WMC-HIEC project are crucial to minimising duplication and repetition of effort and help to achieve a legacy which offers a firm, evidence based foundation for continuing work.

Facilitating a whole system culture change is beyond the scope, duration and capacity of the WMC-HIEC project and further work would be needed to test out the transferability and generalizability of the model proposed in Figure 5.2. Nevertheless, as identified in the peer support project, some recommendations have already been adopted and it is clear that the WMC-HIEC project has raised awareness, stimulated discussion and brought together individuals who may not previously have had opportunities to work collaboratively. Although it is difficult to quantify impact, these interventions, (sometimes formal and frequently informal) are likely to have contributed to and helped catalyse changes already in planning or progress. Some of the factors identified in Figure 5.2 will continue to be investigated by the UoB CLARHC team and by Renal Services colleagues and taken forward through collaborations established during the course of the WMC-HIEC project.

Nevertheless, there is a need for greater understanding of how to devise outcome measures that will differentiate between inter-related and dynamic factors and incorporate effective evaluation of both economic value and quality of life. Measures are also needed to enable benchmarking of quality indicators between organisations and like for like comparison across different patient groups. It is very important also to devise both interventions and evaluation measures that are robust and critical but
also engage staff in appreciative inquiry, not alienate them by appearing to be punitive.

Real opportunities have been identified for better networking and collaboration to improve knowledge exchange and knowledge transfer and to reduce duplication or achieve economies of scale. There is anecdotal feedback to suggest the CKD work stream has raised awareness of the factors implicated in a whole system shift towards the choice of home therapies as a default position and clearer justification of the reasons for other choices of modality.

Equally important, in exploring the opportunities jointly with renal service partners, it has been possible to highlight their confidence, capabilities and readiness to meet the challenges, to develop a culture and supporting systems and processes to deliver an effective, flexible and high quality home therapies programme which also allows a personalised service by enabling and supporting individualised exceptions to be accommodated.

Finally, it seems appropriate to end with a comment offered by the CKD Service User and Carer Forum:

*Even though not all the original aims have fully been achieved, WMC-HIEC CKD project work was not a waste of time: gathering and sharing information has an impact; raises awareness and encourages reflection and critical review. Knowledge exchange is vital to stimulate service improvement.*

(Conclusion from the Service user and carer forum, CKD Dissemination event September 2012)
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